

**2016
ANNUAL
REPORT**

OUR MISSION
TO EDUCATE,
SUPPORT & ADVOCATE
FOR THE

**BLEEDING
DISORDERS**

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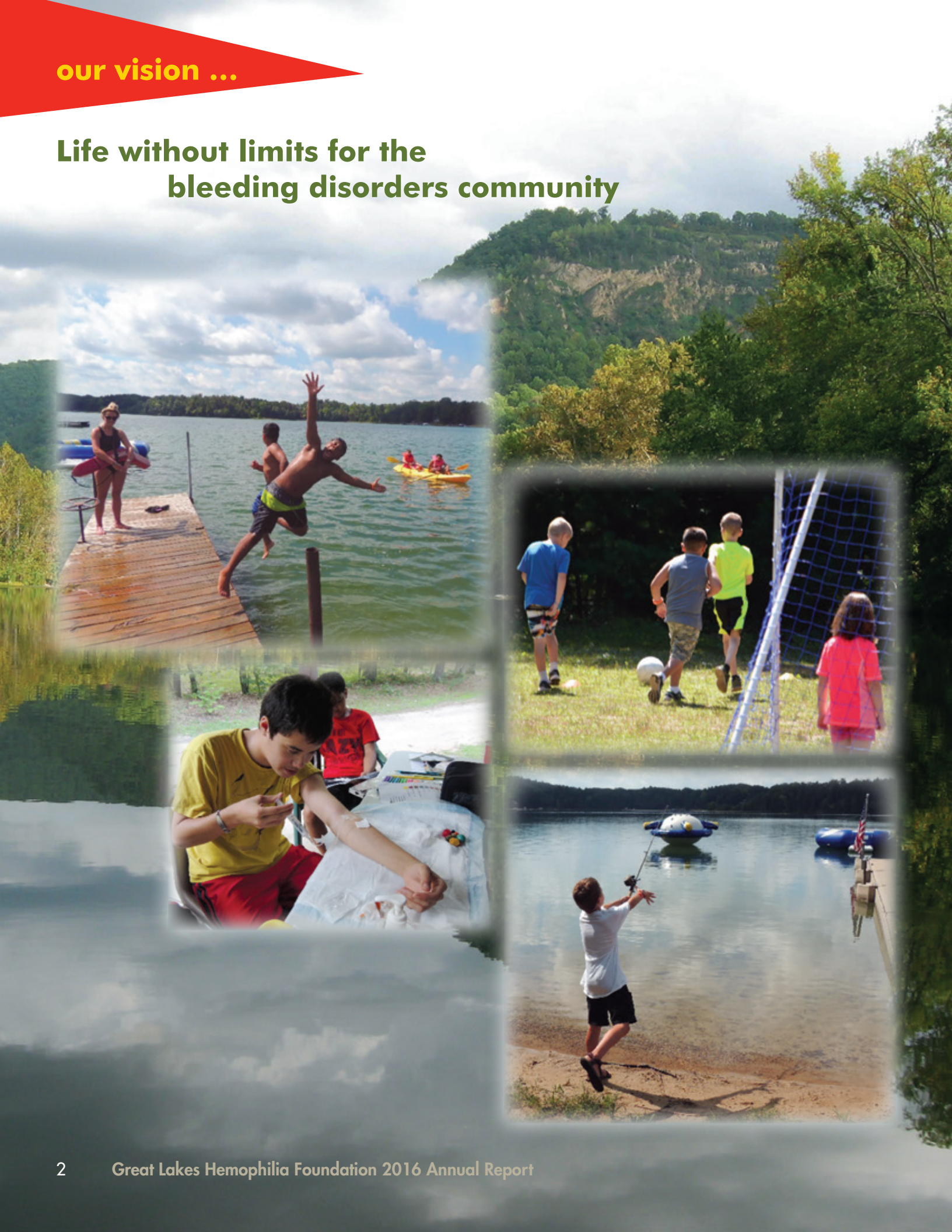
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our vision ...

Life without limits for the bleeding disorders community



Scholarship Program Expanded With Addition of the Jacob N. Shanberge, M.D. Memorial Scholarship Award



Jacob N. Shanberge, M.D.
1922-2004

In 2016, as the result of a very special gift from Ruth Shanberge and her family, Great Lakes Hemophilia Foundation (GLHF) had the good fortune of being able to establish the Jacob N. Shanberge, M.D. Memorial Scholarship Award.

Ruth's late husband, Dr. Jacob N. Shanberge, was a hematologist who dedicated his professional life to the study of bleeding disorders. In 1974, he along with Dr. Richard Aster and one of their patients, Jim Goggins, founded our chapter as part of the National Hemophilia Foundation. Dr. Shanberge was the first President of GLHF's Board of Directors. Ruth shared that his colleagues described him as the "doctor behind the doctor." His research, extensive teaching and lectures earned him worldwide recognition in his field, with many doctors coming to the United States for the opportunity to work in his laboratories.

This scholarship is available to individuals living with a bleeding disorder in Wisconsin, or receiving treatment at a Wisconsin Hemophilia Treatment Center. Applicants must be pursuing a degree in science, medicine or a related field. The intent is to allow Dr. Shanberge's zeal for science and research to continue through

recipients who share his passion and thirst for scientific knowledge. GLHF is extremely grateful for this opportunity to expand our scholarship program in this way, and to Ruth and her family for making it happen.

Emergency Financial Support

Generous donors fund GLHF's Patient Financial Assistance (PFA) services and our educational programs. Our PFA program provides peace of mind to our clients by offering emergency financial support for expenses which, if unmet, adversely affect their general well-being and quality of life. These may include uncovered medical bills, treatments, and any related complications. The program also provides interim assistance with basic living expenses and health insurance premiums.

In 2016, almost half of the PFA that GLHF provided went to cover health insurance premiums. One of the clients that our donors helped was Aaron, a retired gentleman who had exhausted funds that he had carried into

retirement from his employer. These reserves had been covering his premiums. His social worker told us that they had searched for other options, but there were none available, leaving him responsible for the \$1,200 monthly premium. He needed to maintain the adequate coverage in his current policy until a state/federally-funded program was available to him and his family. He may have been able to purchase a policy that was less expensive than maintaining COBRA payments during the time-gap. However, those policies would not have effectively covered the cost of his clotting factor—resulting in other financial challenges. GLHF was glad to have a PFA program that could assist Aaron and his family during this transition.

Red Tie Challenge during the first-ever Annual Bleeding Disorders Awareness Month

Beginning in 2016, the U.S. Department of Health and Human Services approved each March as “Bleeding Disorders Awareness Month,” for inclusion on its calendar of National Health Observances. Obtaining the federal designation provides opportunities to build relationships between state and



TAKE THE CHALLENGE, LOOP-BY-LOOP!

1 Accept the Challenge and get a



2 Get creative and show how you wear that tie!

3 Record your best tie look, pledge to support March as Bleeding Disorders Awareness Month, and challenge a few friends.



4 Post your video with #RedTieChallenge, challenge your followers, and think about making a donation at redtiechallenge.org.



federal legislators, chapters and the community. To commemorate this milestone, the National Hemophilia Foundation (NHF) launched the Red Tie Challenge Initiative during their Washington Days advocacy event. Five GLHF clients and two staff members represented Wisconsin at the event.

NHF introduced the “red tie” as the official symbol of the bleeding disorders community and to serve as an inspiration. The Challenge aims to advance the fight against inheritable bleeding disorders by raising funds for research, education and advocacy initiatives both locally and nationally. RedTieChallenge.org—serves as the movement’s official home on the web. The site includes a donation portal and downloadable materials that students, schools and chapters can use to bring the Red Tie Challenge into the classroom and community to raise funds.

WHY THE RED TIE?

Because it symbolizes the blood ties that bind over 3 million Americans to our community.



Accepting the Challenge

GLHF offered the opportunity to participate in the Red Tie Challenge at our programs and fundraising events throughout the year. A gallery of adults, children and community icons could be seen donning red ties.

Students and faculty of a West Bend school participated in the Red Tie Challenge in honor of their first-grade classmate, Zach. The Student Council sponsored an assembly where they explained bleedings disorders to the school's entire student body. Students were later able to show their leadership and understanding on a special dress-up day by wearing a red tie, scarf, or an item of their choice in honor of Zach. Both adults and children gained an awareness that having a bleeding disorder means you have to be more careful and be sure to be infused regularly. But despite that, Zach is just a normal little boy.

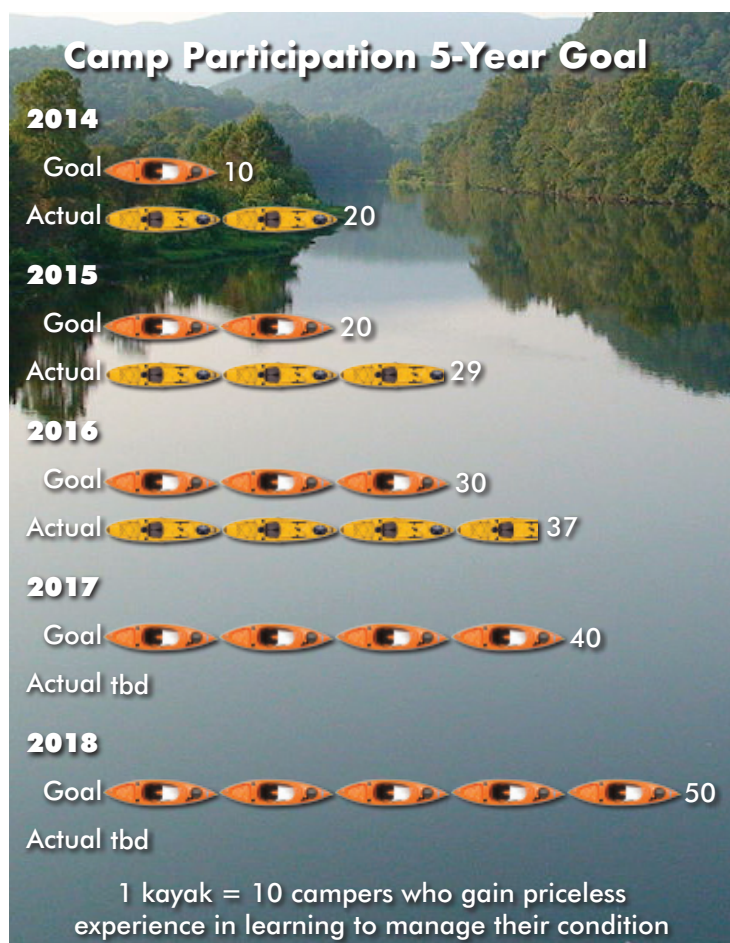
The Student Council donated \$1 to GLHF for each person wearing red on the dress-up day. Additional contributions from individual students and staff members brought the total donation to \$332.69. Our thanks go out to Zach's sister and parents for their part in this and similar outreach efforts on behalf of Zach and GLHF.





This was the third year of GLHF's Camp Klotty Pine (summer camp) program for children ages 7-15 years. Wisconsin's bleeding disorders community has embraced having a camp close to home that includes professional staff who they already know from regular clinic visits. Providing a child with the treatment instruction that is specific to them, and seeing their peers managing the same, makes this informal setting exactly what children need to take on their own self-infusions as they are ready.

GLHF's Family Camp continues to be a strong conduit for Camp Klotty Pine enrollment. Participation in this weekend networking opportunity was expanded in 2016. All families with a child affected by a bleeding disorder were invited to attend and learn together, regardless of a child's age or prior/future attendance at summer camp. Adults and kids got to know one another through participation in activities across a wide array of individual and group activities. We continue to monitor all of our camp programs for continued success and to make sure we are providing children and their families with services and opportunities that meet their needs.



Improving a Camper's Experience

Participating in pre- and post-camp surveys gives children a voice and allows for evaluation and measurement with regard to their learning experience. Feedback is gathered concerning traditional camp activities, relationship building with peers, and treatment/management of their bleeding disorder. Here are a few outcome highlights.

At camp, I...

...was proud of my accomplishments.

100%

...did things that I was afraid to do at first.

80%

...learned new things about taking care of myself and my bleeding disorder.

100%

...felt good about myself.

91%

Camp helped me make new friends.

90%

The Power of Advocacy

We tell our clients that advocacy is simply information sharing. And, when information and stories resonate with members of Congress, they want to know how they can help. NHF's Washington Days is a valuable opportunity where a single person can make all the difference, by educating their Senators and Representatives about what it's like to live with a bleeding disorder. With the federal deficit now in the trillions, one of the government's top priorities is to slash spending. Funding for the national network of hemophilia treatment centers (HTCs) could be in jeopardy. In March five GLHF clients,



accompanied by two staff members, joined hundreds of others like them to tell their stories during Washington Days.

2016's Washington Days Messages to Lawmakers:

- Maintain funding for federal hemophilia programs, including comprehensive treatment services, blood safety and surveillance, inhibitor prevention and research for better treatments.
- Encourage the House to co-sponsor the Access to Marketplace Insurance Act (HR 3742) – Requiring health insurers to accept payments from third parties to satisfy premiums owed by an enrolled individual.

Milwaukee: Location of Two Regional Meetings in Fiscal Year 2016

Region V-West/Northern States Regional Meeting

GLHF, in its role as a Regional Core Center, provides operational leadership to support a network of 14 HTCs. The group's semi-annual meeting, held in Milwaukee, was attended by chapter-staff and healthcare providers from the 5 states that comprise the region.

"Transition Care for Patients with Bleeding Disorders" was presented by Patience White, MD, MA – Co-Project Director, Got Transition - The Center for Health Care Transition Improvement (GotTransition.org). Uninterrupted healthcare is not an option for individuals with bleeding disorders as they transition from adolescence to adult. The keynote address highlighted elements needed to prepare youth, beginning at age 12, through the steps needed to take on their own appointments with adult health care providers.



At age 18, young adults need to be ready with the skills needed to do things such as:

- ✓ Manage their own prescriptions.
- ✓ Talk to an adult doctor.
- ✓ Schedule, prepare and pay for appointments including having info ready to give to providers for proper care/payment.

National Hemophilia Foundation Regional Leadership Seminar

Meetings are held regionally by NHF's Chapter Services team. This was the first time that NHF held their leadership seminar in Wisconsin. Milwaukee's event was attended by 85 staff and board volunteers representing 21 chapters from 18 different states.

The seminars provide a platform for professional education and networking between chapters. High-interest topics and workshop sessions include specific links to their impact for the bleeding disorders community. The tools and skills obtained during these meetings help chapter staff to better support local patients through expanding programming and enhancing fundraising efforts.

Sessions during the 3-day period included:

- ◆ HIPPA and What it Means for Chapters Today.
- ◆ Entitlement, Alliances, Diversity.... How Will You Manage?
- ◆ Youth Empowerment – Understanding Youth Where They Are At / Finding and Working through the Disconnect.
- ◆ Roundtable discussions to learn innovative ideas from other chapters.



**2016 MKE
BEST BLOODY**

1st – Pepi’s Pub & Grill
2nd – Steny’s Tavern & Grill
3rd – Matty’s Bar & Grill

MOST INVENTIVE
 Bounce Milwaukee

MOST LIKE A MEAL
 Café Bavaria

MOST MILWAUKEE
 Steny’s Tavern & Grill

**GREAT LAKES
HEMOPHILIA
FOUNDATION**
 TODAY’S CARE, TOMORROW’S CURE.

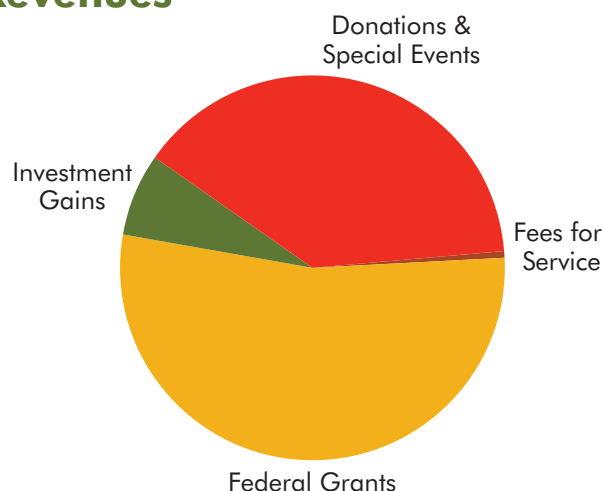
Our two Hemophilia Walks and Milwaukee’s Best Bloody fundraising events continue to show stellar growth. This kind of success can only be achieved with dedicated volunteers who help with planning, and for the walks—raising funds year-round. With over 1,300 participants enjoying those festivities alone, they are providing a great avenue for generating awareness of the expenses and accommodations to daily life that individuals face with these life-long diseases. Thank you to all our event participants, volunteers and sponsors for your inspiration and support of our mission.



Fundraising Event	Registration	Net Income
7th Annual Hemophilia Walks	547	\$63,355
4th Annual Milwaukee’s Best Bloody	847	\$59,866
20th Annual Teeing up for Charity®	62	\$21,086

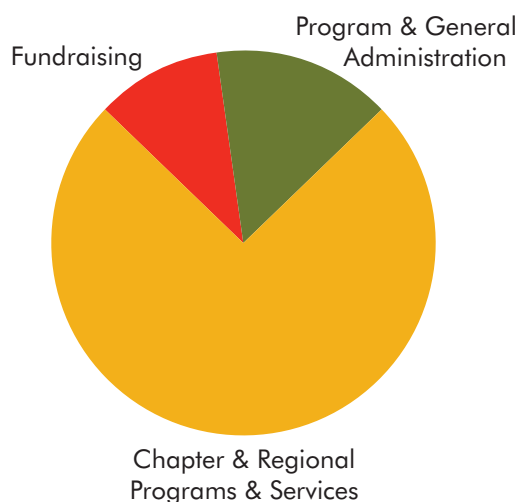


Revenues



• Donations & Special Events	\$ 603,970
• Fees for Services	\$ 12,188
• Investment Gains	\$ 106,907
• Federal Grants	\$ 832,296
Total:	\$1,555,361

Expenses



• Chapter & Regional Programs & Services	\$ 1,093,965
• Program & General Administration	\$ 220,116
• Fundraising	\$ 159,648
Total:	\$1,473,729

- ♦ **Amish Clinic Day –**
140 Adults & Children received transportation to access care
- ♦ **Camp –**
42 Children, laughed, played, and learned (Camp Klotty Pine 37/MN Camp Courage 5)
- ♦ **Family Camp –**
28 Participants learned together (14 Adults /14 Children)
- ♦ **Community Night at Miller Park –**
60 Attendees cheered on the Brewers and shared camaraderie
- ♦ **Medical ID Program –**
\$2,147 of ID Jewelry made 89 clients a little safer, in case of emergency
- ♦ **Patient Financial Assistance –**
130 Clients received \$49,214 in extra help to meet medical and other emergency needs (53 Households/71 Adults/59 Children)
- ♦ **Scholarships –**
\$10,475 helped 9 students reach their education goals
- ♦ **Washington Days –**
5 Clients educated legislators about bleeding disorders
- ♦ **Wisconsin Bleeding Disorders Conference (WBDC) –**
276 Attendees absorbed information
- ♦ **Milwaukee's Best Bloody –**
847 guests and sponsors raised the Net Income of \$59,866
- ♦ **Teeing Up for Charity® –**
62 Golfers teed up to raise the Net Income \$21,086
- ♦ **Hemophilia Walks –**
547 individuals from 36 different teams strolled along to raise the Net Income of \$63,355
- ♦ **Poinsettia/Wreath/Coffee –**
75 people decked the halls on our behalf, raising the Net Income of \$3,911

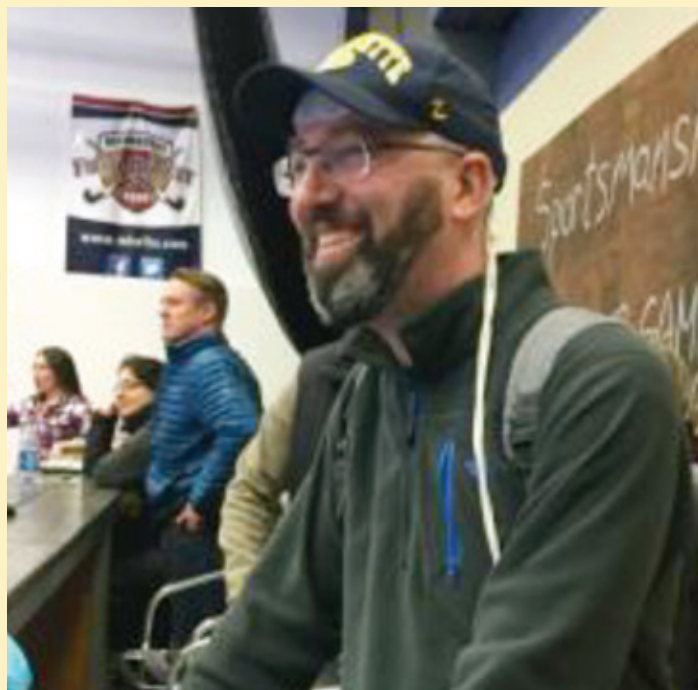
Message from our Executive Director and Tribute to Former Board President, Michael Kohler

Dear Friends,

As I dropped my daughter off for her first day of kindergarten in September 2015, I received a call from one of our board members, Michael Kohler. He was calling to let me know that he had been diagnosed with an aggressive form of brain cancer. As I sat in the elementary school parking lot, my heart broke for Michael, his wife, and their two young daughters.

Despite the frightening diagnosis, Michael remained hopeful and grateful for all who were reaching out to share their love and support. Michael fought his cancer with everything he had....radiation, chemotherapy, experimental treatments, surgeries, and an undying will. In the months that followed, he spent valuable time with his family—coaching soccer, traveling, and watching football. He also remained a champion and leader for GLHF and the bleeding disorders community. As he finished his third board term he joked that as Board Development Chair, he had recruited a dozen new members to replace him. While he said this in jest, it was actually very true. Michael's passion, dedication and leadership could not be matched.

On April 9, Michael lost his 21-month fight with cancer and we lost an incredible advocate, leader, and friend. At his memorial service, his best friend Mark shared lessons that Michael wanted to pass on to his daughters. To paraphrase,



Michael's Lessons ...

1

You don't have to be the smartest person in the room, but work the hardest.

2

One person can make an impact.

3

Attitude matters.

they were; "You don't have to be the smartest person in the room, but work the hardest;" "One person can make an impact;" and "Attitude matters."

Michael was very proud of his work during his nine years on our board. He made an impact through his leadership, member recruitment, and dedication to our mission. He understood that in working for a small population, we need to "work the hardest" to make our voices heard and make sure the needs of our clients are met for care and coverage.

One person does make an impact. We will count on you as we look at the future of GLHF and the needs of our clients. Your donations allow us to educate, support

and advocate through our programs and services like Camp Klotty Pine, the Wisconsin Bleeding Disorders Conference, and patient financial assistance.

And, attitude does matter! As we see changes coming for healthcare, we need to keep our attitude positive as we educate state and federal legislators about the needs of those we serve. We held a successful Wisconsin Legislative Day earlier this year, and are gathering a grass roots advocacy committee, but our work is just beginning. This is an interesting and exciting time. I challenge you to help us continue making life

manageable for the clients we serve, just as Michael did while on our board and continues to do with his legacy message of hard work, impact, and attitude. Thank you for sharing your generosity, talents, ideas, and time on behalf of the bleeding disorders community.

Sincerely,



Danielle Leitner Baxter

Executive Director, Great Lakes Hemophilia Foundation
Regional Director, Region V-West, Northern States



Danielle with Michael - 2013

Mission

To educate, support and advocate for the bleeding disorders community of Wisconsin.



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Peter Fisher,
President

Jeff Koopmeiners
Vice President

Robb Grehn
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Andrew Barragry
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Tracie Fechter

Bill Finn*

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Deb Weiner

Joshua R. Welsh

Gilbert White, M.D.

Raymond Zellmer*

* Term Ended in 2016

Staff Members

Danielle Leitner Baxter
Executive Director/Regional Director

Kailee Frederick
Outreach & Education Coordinator

Duane Herron
Regional Coordinator

Jayne Holmes
Administrative Assistant

Danielle Lennie
Communications Specialist

Karin Koppen
Program Services Coordinator, Camp Director

Jessica Kveen
Special Events Coordinator

Marlene Vidal
Director of Development

You can help our efforts!

Your contributions support the work we do in providing resources and education for individuals and families with bleeding disorders. Every gift is meaningful and important in helping us achieve our financial goals while limiting expenses.

- 1 Provide **financial gifts** in the form of cash, check, money order or credit card.
- 2 Participate in **planned giving** through a bequest or other planned gift.
- 3 Pay **tribute to a family member or friend** with a gift to GLHF.
- 4 Solicit **matching gifts** that make your contribution work harder with the help of your employer.
- 5 Designate GLHF as a recipient of funds from your employer or insurance company's **charitable donation program**.
- 6 Donate to our **Wish Lists** to help us hold down costs associated with program events including craft supplies, sports and office equipment, bug spray, professional services and more.
- 7 Sponsor one of the **speakers or activities** at our educational conference allowing us to broaden the opportunities we can provide.
- 8 Attend, sponsor or supply an auction/raffle item for our events – **Milwaukee's Best Bloody or our Hemophilia Walks**.
- 9 Purchase a locally grown **poinsettia or wreath** for yourself, an office or gift giving.

For more information on becoming a volunteer or making a contribution, please contact our Development Team at info@glhf.org or 414.937.6783.

